



## Nevada Early Intervention *Summer* Family Newsletter

July-August 2015 Volume 5 No 4

### Message from Part C's State Family Resource Coordinator, Information & Referral... **HAPPY FOURTH of JULY!!!**

Dear Parents/Families

An opportunity to attend... **MEETING NOTICE**

#### STATE EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL (ICC)

Date and Time of Meeting: **Thursday, July 16, at 9:00 a.m.**

Meeting will be held via Video Conference at the Following Locations:

- **Las Vegas:** ~~Nevada Early Intervention Services~~ [call for new location!]  
1161 South Valley View Blvd., Conference Room
- **Reno:** Nevada Early Intervention Services  
2667 Enterprise, Conference Room
- **Elko:** Nevada Early Intervention Services  
1020 Ruby Vista Drive, Conference Room

Nevada's ICC was set up to advise and assist Nevada in the development and implementation of a statewide system of early intervention services for young children with developmental delays or disabilities and their families. Families and community partners are invited to all ICC meetings.

It is especially important to hear from families and I encourage you to participate. If you would like more information about attending meetings or how to submit public comments to the Council, please contact me at: [ddinnell@dhhs.nv.gov](mailto:ddinnell@dhhs.nv.gov) or [ProjectAssist@dhhs.nv.gov](mailto:ProjectAssist@dhhs.nv.gov) or call Project ASSIST at 1-800-522-0066

Sincerely,  
Dan Dinnell

\*Web Address: <http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>



Cheryl, Eric, and Dan

#### NEVADA's EARLY INTERVENTION SERVICES

IDEA Part C Office  
4126 Technology Way, Suite 100  
Carson City, NV 89706  
Office: (775) 687-0587  
Fax: (775) 687-0599

**Project ASSIST**  
**1-800-522-0066**

[ProjectAssist@dhhs.nv.gov](mailto:ProjectAssist@dhhs.nv.gov)

Please enjoy the stories shared of families who have "been there and done that!" — See page 2.

**NV Disabilities Conference**  
— See page 3.

**FREE....** Participation in the national **EARLY INTERVENTION FAMILY ALLIANCE (EIFA)** is open to *all* interested in supporting early intervention. . . **Keep informed! Obtain Answers! Impact Policies!**

The **EARLY INTERVENTION FAMILY ALLIANCE** is a national leadership organization dedicated to improving outcomes for infants and toddlers with disabilities and their families.

Members receive email alerts and updates on key early intervention topics and can join the **EIFA** list serve to participate in active discussions and share experiences. Web: [www.eifamilyalliance.org](http://www.eifamilyalliance.org)

If you are interested in volunteer activities, the STATE EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL (ICC) has a permanent **FAMILY SUPPORT RESOURCE SUBCOMMITTEE (FSRS)** that can always use parents and others who have a passion for supporting early intervention.

Contact: [ProjectAssist@dhhs.nv.gov](mailto:ProjectAssist@dhhs.nv.gov) or call 1-800-522-0066

The Part C Family Newsletter has opportunities to suggest and share... You are invited to submit articles, share your story, or include your child in a Family Spotlight, with a photo. (All items are subject to editing and review.)

# Been there, done that!



"There's that moment when you are carrying a baby that the feeling of their little feet kicking inside you is pure bliss. Not everyone is able to experience that. While I was lucky enough to get pregnant, my body struggled to keep that life going inside. I spent incalculable hours fearing the worst and vowing to save the life of my unborn baby at any cost. But no one ever really talks about that cost. Two of my three children were born with completely different medical and genetic conditions. My oldest was born with one side of his face paralyzed, some crainiofacial deformities, autism, and a

decreased ability to regulate his nervous system (breathing, body temperature, sleep, etc.). My youngest was born with microcephaly, most likely caused by mitochondrial disease. They will tell you that these children are "special," and will teach you more about life than any classroom could ever offer. And while this is true, it doesn't make caring and fighting for them any easier.

I was given a gift last year when my children's developmental specialist and social worker, respectively, handed me a slip of paper, one for the Nevada PARTNERS IN POLICYMAKING class, and the other to be a parent representative on Nevada's Early Intervention INTERAGENCY COORDINATING COUNCIL (ICC). That was the beginning of my parent advocacy journey. Through speakers and friendships made at PARTNERS IN POLICYMAKING, and active discussions on the ICC, it was evident to me that there is a disconnect between people and the programs that deliver services. Parents I speak with are often not even aware of the resources they have, how to access them, or even that there are multiple Early Intervention providers to choose from. Moreover, most of the parents I meet, including myself, don't understand or know how to ask for certain services or really grasp what our parent rights actually mean.

For these reasons, my husband and I set in motion a project that will forever change our role in our children's lives. We created the ***Nevada Parent Advocacy Initiative***. With the help of early intervention providers, the Nevada Governor's Council on Developmental Disabilities, and most importantly, other parents, we are working to create a strong community of parent advocates. This project consists of a parent Facebook support page for families with children in Early Intervention Services, comprehensive brochures that give parents all the basic information they need to access and utilize services effectively, and a website that consolidates the wealth of knowledge of everyone who is part of this system. It's all the insider information about Early Intervention in one common place.

We ask that, as parents and caregivers, we stand together as a strong community and help each other to face our fears, find the courage to embrace our differences, to get involved, and to share the joy that our children bring us. Our lives, and our children's lives, may not always be filled with bliss, but together, I truly believe, that we can achieve something really remarkable". – Aimee Hadleigh, ICC Parent Representative

Nevada Parent Advocacy Initiative: [www.nvparents.com](http://www.nvparents.com)

Facebook: [www.nvparents.com/fb](http://www.nvparents.com/fb) or search for "Early Intervention Parents NV" in Facebook

# NEVADA Disabilities

**CONFERENCE 2015**

**Break Barriers → Open Doors**

**Get Registered Now!!!** Join us for the 2015 Nevada Disabilities Conference (NDC2015), two days of state-of-the-art information on improving the health and lives of individuals with disabilities and children and youth with special health care needs, and their families. This conference is a one-stop platform for connecting to new trends, helpful resources and best practices.

With 55 vendors or resource tables planned and an outstanding agenda, featuring expert speakers and special sessions addressing today's greatest challenges, we will strive to Break Barriers ⇨ Open Doors!

This is a great opportunity for families and individuals affected by disabilities or special health care needs, administrators, healthcare professionals, educators, students, caregivers, advocates, policymakers, service providers to learn about various topics of interest, such as:

- **advocacy • Assistive Technology • early intervention • special education • futures planning • recreation • health & dental care • building community • service supports • independent living • inclusion • transition • self-determination • respite • and more.**

For more information contact Family TIES Statewide  
at [ndc2015@familytiesnv.org](mailto:ndc2015@familytiesnv.org) or (866) 326-8437 / [www.familytiesnv.org](http://www.familytiesnv.org)

WEBSITE ONLINE

[Nvdisabilitiesconference.org](http://Nvdisabilitiesconference.org)

This conference will be held concurrently with the National Association of Councils on Developmental Disabilities (NACDD) Annual Meeting, bringing leading experts in the field of disability to Nevada, offering more resources and giving national attention to our state.

Be a part of this dynamic event where innovative strategies and shared knowledge come together in an exciting forum for change. **Plan on it!!! — July 20 & 21, 2015 — At the Nugget in Sparks, NV**



## **Great Conference Keynotes You Don't Want to Miss!**

**Monday morning**

**Josh Hanagarne** couldn't be invisible if he tried. Although he wouldn't officially be diagnosed with extreme Tourette Syndrome until his freshman year of high school, Josh was six years old when he first began exhibiting symptoms. When he was twenty and had reached his towering height of 6'7", his tics escalated to nightmarish levels. Determined to conquer his affliction, Josh tried countless remedies, with dismal results. At last, an eccentric, autistic strongman taught Josh how to "throttle" his tics into submission using increasingly elaborate feats of strength. What started as a hobby, in his spare time he trains for strongman competitions, became an entire way of life—and an effective way of managing his disorder. He overcame his own case of Tourette Syndrome and is now working to help others.



Today, Josh Hanagarne is the proud father of five-year-old Max, husband, avid reader, librarian at Salt Lake City's public library, weight lifter extraordinaire, founder of a popular blog about books and weight lifting—and the author of the amazing book, *"The World's Strongest Librarian: A Memoir of Tourette's, Faith, Strength, and the Power of Family."* He believes in curiosity, questions, strength, and that things are never so bad they can't improve. He has given numerous presentations around the country and was a key presenter at the 2011 Office of Special Education Projects' Mega Leadership Conference in Washington, D.C.



## **Great Conference Keynotes You Don't Want to Miss!**

### **Tuesday morning**

**Robert Naseef, Ph.D.**, is the father of an adult son with autism, and has "a foot in each world" as a father and a professional. He received his doctoral degree in psychological studies from Temple University and has practiced for over 20 years as a psychologist. He has a full-time independent practice in Philadelphia, in psychology that specializes in working with families of children with autism and other disabilities or special needs.



Dr. Naseef has a broad background in both education and psychology, and was instrumental in developing a training package to foster parent-professional collaboration for the New Jersey Department of Education, Division of Special Education, and taught graduate courses at Antioch University in Philadelphia and Rider University in Lawrenceville, New Jersey. He served as field supervisor for doctoral students from Rutgers University Center for Applied Psychology. He was a faculty member at

American Healthcare Institute where he taught courses in childhood mood, anxiety, and developmental disorders. He holds clinical privileges in psychology at Penn Behavioral Health, University of Pennsylvania Hospital, serves on the board of directors of the Center for Autism, and the professional advisory board of the Philadelphia Autism Center for Excellence.

In 2008, Robert Naseef was honored by *"Variety, the Children's Charity"* for his outstanding contributions over the past 20 years to the autism community.

He has published in scholarly journals and other publications including several books, *"Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child With a Disability"*, and *"Autism in the Family: Caring and Coping Together"*. He is the co-editor with Dr. Cindy N. Ariel of *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*. *"Living Along the Autism Spectrum"* is a DVD which features him with Stephen Shore and Dan Gottlieb.

Dr. Naseef has lectured nationally and internationally on issues related to family life with special needs and was invited as a key presenter at the 2014 World Autism Congress in Kuwait City. He has appeared on radio and television. He has a special interest and expertise in the psychology of men and fatherhood, and facilitates a "Google Hangout" called, "Guy Talk", hosted by AutismBrainstorm.org, where they discuss specific topics as an online resource to support fathers and strengthen families.

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### **Tuesday at noon**

**Aaron Bishop** was appointed Commissioner of the Administration for Intellectual and Developmental Disabilities (AIDD) within the U.S. Department of Health and Human Services in March 2014, having served as Acting Commissioner since November 2013. AIDD provides financial and leadership support to organizations in every state and territory in the United States to ensure that individuals with intellectual and developmental disabilities and their families can fully participate in and contribute to all aspects of community life.



Mr. Bishop has almost 20 years of experience working with and for individuals with disabilities in both the direct practice and public policy sectors. He was the Executive Director of the National Council on Disability from November 2010 until February 2013. In 2006, he received a Kennedy Foundation Public Policy Fellowship to work on federal disability policy and legislation for the U.S. Senate Committee on Health, Education, Labor and Pensions.

Mr. Bishop's previous experience also includes serving as the Project Coordinator for the Waisman Center University Center for Excellence in Developmental Disabilities, where he managed projects that advanced the rights of individuals with disabilities. He also served as the Site Coordinator and Director of Technical Assistance for the National Service Inclusion Project for the Association of University Centers on Disabilities.

Mr. Bishop received his Master's of Science in Social Work, with an emphasis in public policy, and two Bachelor's of Science in Natural Sciences from the University of Wisconsin-Madison.



For Families & Professionals

**EARLY CHILDHOOD SPECIAL EDUCATION *LIBRARY*—**

*There are a great many things to learn... check them out!!!*

**NEW Books!!!**

***"Parenting Children With Health Issues: Essential Tools, Tips, and Tactics for Raising Kids With Chronic Illness, Medical Conditions, and Special Healthcare Needs"*** – Does your child have a health condition which requires special medical or dietary care? Whether your child has ADD, allergies, asthma, cystic fibrosis, diabetes, Down Syndrome, developmental delays, an eating disorder, hemophilia or any other special need, you'll find essential parenting skills to respond to your child's emotional needs, help your child cope with health challenges, comply with medical requirements and live a hope-filled life.

***"The Common Sense Guide to Your Child's Special Needs: When to Worry, When to Wait, What to Do"*** – If you have a child who is struggling, who is not meeting her/his developmental milestones, Dr. Pellegrino clearly explains to parents what are the next steps to take. – Section 1 entitled "Understanding Your Child," goes into details about common areas of concern – Section 2 entitled "Special Children, Special Needs," focuses on hearing, vision, and sensory problems. Also, Dr. Pellegrino has a chapter on Special Medical Problems where he gives information on basic health care of children with special needs.

***"A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs"*** – Every parent dreams of having a happy, healthy child. What happens when these dreams are shattered by a physical or cognitive disability? The writings collected here are grouped into chapters reflecting the progressive stages of many parents' emotional journeys, starting with grief, denial, and anger and moving towards acceptance, empowerment, laughter, and even joy.

***"Autism in the Family: Caring and Coping Together"*** – How can parents provide the best support for their child with autism—and ensure that the whole family's needs are met? This book has answers with keen insight, reassuring honesty, and practical guidance. A practicing psychologist and father of an adult son with autism, Dr. Robert Naseef [Will be giving a Keynote Presentation at the **Nevada Disabilities Conference**] has both personal and professional expertise to share with overwhelmed families, weaving wisdom from years of clinical practice with candid first-hand insights on parenting a child from birth through adulthood.

***"The Early Intervention Guidebook for Families and Professionals: Partnering for Success"*** – This practical guide is essential reading for both professionals and families of infants and toddlers with, or at risk for, developmental delays or disabilities. The Early Intervention Guidebook shows what early intervention looks like when it is based on current research, policies, and best practices. It focuses on how families and professionals can collaborate effectively so that young children learn, grow, and thrive. Specific components of early intervention evaluation and assessment, program planning, intervention implementation, service coordination, and transition are discussed in every chapter.

These library materials are available for use statewide. For more information, contact your service provider or coordinator. If you have questions or recommendations for the Library, contact **Project ASSIST** toll free **1-800-522-0066** or [ProjectAssist@dhhs.nv.gov](mailto:ProjectAssist@dhhs.nv.gov)

Catalog at: <http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST/Special-Ed-Library/>

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**The Magic of Everyday Moments - Series 2**

Source: ZERO TO THREE - April 14, 2015

Four new videos have been added to ZERO TO THREE **The Magic of Everyday Moments** series. Each video shows how parents can nurture key skills and attributes children need to be eager, competent learners and to form strong, healthy connections with others as they grow - all through everyday interactions and routines. [Series 2](#) includes:

- 1) Development From Birth to 12 Months Old: Forming a Trusting Bond to Nurture Learning
- 2) Development From 12 to 24 Months Old: Strong, Positive Connections and Interactions Fuel Learning
- 3) Development From 24 to 36 Months Old: New Skills Develop Through Play, Routines, and Relationships
- 4) School Readiness: Foundations in Language, Literacy, Thinking, and Social-Emotional Skills

At: <http://www.zerotothree.org/parenting-resources/MOEM/moem-series-2.html>

## EARLY INTERVENTION PROGRAM ACTIVITIES OR EVENTS FOR FAMILIES AND FRIENDS

### NORTHEASTERN NEVADA EARLY INTERVENTION SERVICES

\* contact your Developmental Specialist/Service Coordinator for more information

#### ⇒ Nevada Early Intervention Services—Elko:

- The **Family Support Group** is for **ALL** of those families with children with any type of special needs. Join us the first Thursday of each month from 5:45 to 7:30pm [except for Summer months activities or other special events] at Nevada's Early Intervention Services Office in Elko. To RSVP contact Janina Easley at [jfal84@yahoo.com](mailto:jfal84@yahoo.com) or call 775-828-5153.

### NORTHWESTERN NEVADA EARLY INTERVENTION SERVICES

\* contact your Developmental Specialist/Service Coordinator for more information

#### ⇒ Advanced Pediatric Therapies—Reno:

- **Community Play groups** at Pah Rah Park every 2nd & 4th Friday, each month at 10:30am. Lots of fun games and activities for the kids. Families should call for more information—775-825-4744.
- We will be hosting a feeding conference called **Mealtime Miseries** on August 28th and 29th at Saint Mary's Hospital.

#### ⇒ Nevada Early Intervention Services—Reno:

- **Family Support Group**, sponsored by Down Syndrome Network of Northern Nevada & NEIS - The 1<sup>st</sup> Thursday each month [except for Summer months activities or other special events] 5:45 pm, at NEIS. Call 775-828-5159 or e-mail [dsnninfo@gmail.com](mailto:dsnninfo@gmail.com) to R.S.V.P.
- **Family TIES** provides family support in filling out **Medicaid/SSI and other Social Services applications** every 2<sup>nd</sup> Monday from 10am-12noon at NEIS, by RSVP only! Please call 775-823-9500 to RSVP.
- **RAVE** will have **Respite Applications** available every 2<sup>nd</sup> Monday from 10am-12noon at NEIS.
- **Friends of Special Children** - This non-profit has supported families at NEIS in so many ways both financially and physically. If you are interested in being a part of this great cause, contact Lori Schoen at 688-0379 or email: [lschoen@health.nv.gov](mailto:lschoen@health.nv.gov)
- **Hands and Voices** meets at NEIS, usually the 4<sup>th</sup> Thursday of every other month on the "odd" months, at 6:00 pm. Contact 351-1959, or email: [info@nvhandsandvoices.org](mailto:info@nvhandsandvoices.org)

#### ⇒ The Continuum—Reno:

- **Carousel Kids** specializes in early childhood education, and is an inclusive childcare where all children are recognized for individuality and different abilities. We also offer an intergenerational experience where children interact with elders from Regenerations, our onsite adult day program. For more information or to schedule a tour, phone: (775) 829-4700.
- **Grandparents raising grandchildren with special needs — Support Group**, 3700 Grant Dr., Reno. First Thursday monthly, with free childcare on site. For more information call Amanda Aitchison at (775) 737-8756.

### SOUTHERN NEVADA EARLY INTERVENTION SERVICES

\* contact your Developmental Specialist/Service Coordinator for more information

#### ⇒ Easter Seals Nevada—Las Vegas:

- **Playgroups** on Fridays. Come Join the Fun! For more information call or email Ella Philander, at 428-4335 or [ella.philander@eastersealsnevada.org](mailto:ella.philander@eastersealsnevada.org)

#### ⇒ ISS Baby Steps—Las Vegas:

- At the **Inspired Discoveries playgroup**, we welcome children who are between the ages of 0-3 years old. We will explore & learn in an inclusive setting for all children. We also hope that by providing family to family connections, supports, and resources we can help empower and educate individuals and their families. Please join in on our fun, learning adventure!" Call: (702) 279-4174

#### ⇒ Nevada Early Intervention Services—Las Vegas:

- **Parent meeting** for families of children (any age) with Prader Willi Syndrome, at NEIS. Contact Erica Magana (Bilingual) at 486-9265 [emagana@adsd.nv.gov](mailto:emagana@adsd.nv.gov), or Shirley Farkas 486-9263 [sfarkas@adsd.nv.gov](mailto:sfarkas@adsd.nv.gov)

#### ⇒ Positively Kids—Las Vegas:

- Get ready for our **Annual Duck Fest**. Fun for the entire family, September 19th at Town Square. Starts at noon!!!!
- **Neo-Pediatric Clinic** — Do you have a child that was born before 37 weeks? Do you have concerns? If yes, call now to see our Neonatologist Dr. Abdulla. Phone: 702-262-0037

#### ⇒ Therapy Management Group—Las Vegas:

- **Milagros Escondidos** family support group, last Thursday of the month, 6-8pm, at 6600 W. Charleston Blvd., Ste. 111
- TMG is partnering with Family to Family and conducting twice a week **inclusive developmental playgroups**. Contact: Sarah Petrocelli @ 340-5521 or [spetrocelli@tmgnv.com](mailto:spetrocelli@tmgnv.com)
- **Mom's Planning Committee**—Meetings will be at TMG on the 3rd Saturday of the month. Email Martha at [mestrada@tmgnv.com](mailto:mestrada@tmgnv.com) or call (702) 595-5437 X 205.
- **2015 Nevada Disabilities Conference** — Come visit our booth!!! And see our staff present on early intervention!



<http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>

Nevada's Central Directory website is filled with information and resources, including a "Links" page with all kinds of useful websites for information, and a Frequently Asked Questions page.

To receive the newsletter electronically and to make sure you don't miss out on useful information, please send your e-mail address to Dan Dinnell at [ProjectAssist@dhhs.nv.gov](mailto:ProjectAssist@dhhs.nv.gov)

